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ADMINISTRATIVE RECORD

American Journal of Industrial Medicine 23:161-169 (1993)

NIOSH-00213322

Experiences of a State-Sponsored Notification and Screening Program for Asbestos Workers

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Worker notification can involve a broad range of activities including medical screening, personal and mass communications, cohort identification and tracing, and even litigation. The inclusion or exclusion of various supporting activities in a worker notification program may pose significant medical, public health, financial, logistical, and even legal implications for targeted individuals as well as for the agencies involved. This report describes some experiences in a state-sponsored notification and screening program of approximately 4,500 asbestos workers in Minnesota. In this program, a variety of factors led to the decision to provide medical screening to 1,101 workers and 451 spouses. It is anticipated that another 3,400 workers will be notified but not screened. A follow-up survey of notified workers showed overwhelming support for this program. It is estimated that this program will cost more than \$650,000 by its completion. The decision to institute medical screening and other support activities should be made with careful consideration of the diverse implications of these activities to the individuals, communities, and agencies involved. © 1993 Wiley-Liss, Inc.

Key words: high-risk worker notification, risk communication, medical screening, asbestos

INTRODUCTION

Although there is a growing consensus about the need or obligation to conduct worker notification, relatively few practical examples of the methodology of notification have been available. Fortunately, the situation is rapidly changing due in part to NIOSH workshops as reported in this Journal. Worker notification can involve a broad range of activities: mass communications; individual communications; involvement of medical, public health, and social services; cohort identification and tracing; programmatic interventions; epidemiologic, social, or clinical research; and program evaluation. The decision to include or not to include a given component, such as medical screening, may have medical, public health, social, political, financial, and even legal implications. In addition, activities such as medical screening, cohort identification, and tracing can impose significant costs and logistical demands when the cohort is relatively large. The experiences of agencies that have conducted noti-

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Accepted for publication August 24, 1992.

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fication activities may provide some practical perspectives and examples for those who are developing resources and protocols for their own programs.

We present here some experiences from a state-sponsored notification and screening program of a previously unknown cohort of asbestos workers in Minnesota. This case illustrates the broad spectrum of activities that might accompany a worker notification program, particularly when little information is available at the outset about the cohort or its risks.

BACKGROUND

In 1986, representatives of the United Paperworkers International Union (referred to hereafter as the Union) contacted the Minnesota Department of Health (MDH) about a possible epidemiologic study of workers formerly employed at the Conwed Corporation plant in Cloquet, Minnesota. The Union had become aware of asbestos-related diseases among some members of its local. Asbestos was used at this plant in the production of fire-rated ceiling tile and wallboard between 1958 and 1974. At any one time, the plant employed ~1,000 workers. Over the whole 1958-1974 period, at least 4,000 individuals were likely to have been employed. Complicating the issue was the fact that the company was sold in 1985, most workers at the Cloquet plant were terminated, and a litigious environment had developed between the Union and the company.

Shortly thereafter, the Union conducted a medical screening of several hundred former employees (drawn from a 1966 Union seniority list) who were likely to have had significant exposure and adequate latency. In addition, the state requested personnel records, industrial hygiene records, and related information from the company, first on a cooperative basis, then through court action.

GOING BEYOND NOTIFICATION

The Union screening study revealed a high prevalence of asbestos morbidity among the screened workers [Robins and Green, 1988]. This study was extremely important in that 1) it provided convincing evidence that significant asbestos exposures had occurred among certain workers, 2) it drew public attention to the situation, and 3) it was instrumental in the development of subsequent resources. However, neither the Union study nor other information available at that time (early 1988) could answer many of the questions and concerns that needed to be addressed before launching a full-scale notification effort or determining the need for other supporting activities. Consequently, the health department evaluated the need, costs, and design of another much larger medical screening program (1,000-1,500 individuals) as the next step.

Concerns about a large-scale screening focused mostly on the fact that screening programs have not been shown to be effective in reducing mortality from lung cancer and other asbestos-related diseases. There was also concern about potential negative impacts of screening, such as false negatives and false positives, diagnostic costs to individuals, and demands on local medical resources. On the other hand, a large-scale screening program could be justified in this situation for several reasons.

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1. Although there is a vast literature on occupational asbestos exposure, existing studies of asbestos workers did not include a directly comparable cohort.

2. No industrial hygiene data on asbestos levels appeared to be available for any location or time period in which asbestos was used in this facility; therefore, risk profiles could not be established on the basis of ambient exposures but would have to depend on biological or clinical markers of exposure (e.g., pleural changes noted on chest X-ray).

3. The Union-sponsored screening included only selected workers in presumed high-risk departments who had at least 15 years of latency. Screening a larger and broader cross-section of employees would better define the risk profiles of this cohort. In the absence of monitoring data, this information would provide the basis for determining the content of subsequent notifications and the targets of those notifications.

4. There were concerns about community and household exposures; therefore, it was decided to screen spouses of workers as a sentinel for both types of exposures.

5. It was thought that screening might be more effective than notification alone in communicating risks, reducing smoking rates, and other desired outcomes (e.g., seeking medical follow-up).

6. Clinical evidence of asbestos exposure would become an important part of a person's medical history and routine care.

7. Many former workers still resided in the general area, allowing for a single, centralized screening facility that would be readily accessible. Through various Union lists, names and addresses were available for ~1,000 workers within the state (representing, perhaps, about 25% of the total number employed between 1958 and 1974).

8. Widespread publicity about the exposure and the screening program would serve to identify additional workers (despite a court order, it was not known if or when company personnel records would be available or how complete they might be).

9. Most potential participants would have limited resources to obtain comparable medical evaluations on their own, since many former workers had remained unemployed and without medical insurance following the plant closing.

10. Participation of local and regional public health agencies in a screening program would develop and enhance an ongoing capacity to identify and address asbestos-related health issues.

11. There was union, political, and community support for a screening program, and financial resources were expected from the state legislature.

In March, 1988, the Minnesota Legislature passed legislation directing the health department to conduct a medical screening program to "study the existence of asbestos-related diseases among people employed at the plant during [1958-74], evaluate their health care needs, and provide medical and scientific data to coordinate future health screening, counseling, and treatment activities among these people and their families." An allocation of \$150,000 was made for this purpose. A report to the state legislature and recommendations from this screening were due 1 year later.

PRACTICAL IMPLICATIONS OF MEDICAL SCREENING

The decision to conduct a medical screening as part of the initial notification added enormously to the cost, complexity, and logistical demands of the program.

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Although every attempt was made to reduce costs and complexity where possible, there was also a concerted effort to maximize the usefulness, effectiveness, and possible scientific yield from the screening. Some screening-related activities are described below.

Communications

The screening required the communication of many different messages at various times to different audiences through several mechanisms. The main form of communication was a personalized letter. All correspondence was personalized to increase the likelihood that subjects would respond. Several different letters had to be sent to individuals and to physicians before, during, and after the screening. The initial notification letter informed the worker of the possible exposure to asbestos and that the individual and spouse might be eligible to receive a free medical screening. A return form was enclosed. Two follow-up letters were sent to nonrespondents. A second letter was then sent indicating the person's screening appointment time and describing the screening process. Also enclosed were a copy of an informed consent form and a questionnaire asking about respiratory symptoms, work history, smoking history, etc. One day before their appointment, individuals were given a reminder phone call. At the screening site, a trained interviewer reviewed the informed consent form and the questionnaire with the individual and answered questions.

Individuals who, during the screening, were found to have medical problems (asbestos-related or not) requiring immediate attention were sent a letter and received a follow-up phone call several days later to ensure that they had received the letter and understood its contents. Where authorized by individuals a more technical letter was also sent to their physician describing the basis for referral. These individuals received a second follow-up call several months later to ascertain whether they had seen their doctor, what diagnoses were made, and which resources paid for these medical services.

Approximately five months after the completion of the screening, individuals were notified by mail of all their screening results. This was the most difficult communication, since it required the rapid dissemination of complex and possibly confusing screening test results to a large population ($N = 1,552$). This mailing included a lengthy cover letter, which presented some overall findings and a strong recommendation to discuss the results during the next physician visit, a computer-generated report with the detailed screening test results, a glossary of information, and a description of smoking cessation programs available in the area.

Prior to the screening, letters were sent to all relevant physicians in regions of the state in which most former workers resided. This letter informed them about the exposures, the state-sponsored screening program, the tests that would be given, and where they could obtain additional information. In almost all cases, the participants authorized sending their test results to their physician. Again the results were computer generated, and then the reports were grouped by physician. All letters to the same physician were bundled together, and a single cover letter was enclosed.

Immediately after test results were sent to individuals and their physicians, a town meeting was held at the local high school to discuss the screening results and to answer questions. Present at the meeting were representatives from four state agencies, the county health department, the Union, and the medical community. Attorneys and elected officials were also present. The meeting was televised by local cable

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television. A "know your rights" sheet was distributed that described potential medical, legal, and other resources to which individuals may be entitled because of their asbestos exposure. Press conferences were held in the community prior to the screening and at the time of the town meeting at the conclusion of the program.

Collaboration With Other Institutions and Agencies and Community Involvement

Many agencies and institutions were invited to participate in the planning, implementation, and evaluation of the screening. To the extent possible, local agencies had a major and highly visible role in the screening. In addition to local program support and facilities, we required significant publicity and community awareness of the program to encourage participation. Furthermore, it was anticipated that the screening could have a substantial impact on the community, such as increased demands on local medical, public health, and human services agencies. Carlton County Health Services provided personnel, training, education, information, counseling, media liaison, and other support services.

Although NIOSH offered a screening van and personnel, the screening was conducted at a local community hospital after it was ascertained that the hospital could meet the demands of the program. A community liaison task force was established to assist and advise the MDH in many areas of community relations such as soliciting participation, communications, and developing resources for individuals in need. Other institutions such as the Midwest Center for Occupational Health and Safety and the Duluth Clinic participated in the planning, training, and execution of the clinical aspects of the screening. NIOSH assisted in developing the protocol for chest X-rays (films, procedures, quality controls, identification of readers, etc.).

Other Screening Activities

Many individuals had to be hired and/or trained for the program, including interviewers, pulmonary function technicians, on-site coordinators, and volunteers. A full-scale pilot test was conducted prior to implementation of the screening, and several modifications were subsequently made to the protocol. Computer programs were developed to aid in the scheduling and rescheduling of screening appointments. A list of individuals who were willing to come in on short notice was used to fill last minute cancellations. These efforts allowed us to screen 1,552 individuals (1,105 workers, 451 spouses) over 33 work days, with 91% of the potential appointment times filled.

A major concern was the known interreader variability in evaluating chest X-rays for pneumoconioses [see, e.g., Ducatman et al., 1988; Parker et al., 1989]. Several steps were taken to minimize this problem. With the assistance of NIOSH, readers were identified who met three criteria: 1) board-certified in radiology, 2) NIOSH-certified B-reader, and 3) active member of the American College of Radiology Task Force on pneumoconioses. For cost purposes, two (rather than three or more) readers were selected (although the pulmonologist who evaluated the X-rays continuously during the program for immediate referrals was also a B-reader). A modification was added to the standard ILO protocol to determine whether greater reader concordance could be achieved by taking advantage of self-reported medical and smoking history and body mass index. This modification asked the reader to decide if radiographic changes that were "consistent with" pneumoconioses were.

given the medical history, due to dust or to some other cause. A description of this modification and its performance is in preparation.

Costs of Screening

The state legislature appropriated \$150,000 to conduct screening of ~1,000 individuals. An additional grant of \$10,000 was received from the Duluth Clinic Foundation. These funds paid for contracted services, expenses and supplies, and temporary employees. Staff time, however, amounted to an additional \$150,000. About 12 members of the epidemiology, programming, and clerical staff in the Chronic Disease and Environmental Epidemiology Section contributed some portion of their time to the notification and screening program. Our best estimate is that the notification/screening phase cost ~\$326,000 through March, 1989 (after the final town meeting to present results). These costs do not reflect, of course, the cost to individuals or to their insurance providers for any medical follow-up, for missed work to attend the screening, or for other indirect costs.

OTHER CONWED FOLLOW-UP ACTIVITIES

The screening program fulfilled most of its objectives [MDH, 1989]. The findings confirmed that there had been significant potential exposure to asbestos at the Conwed plant in Cloquet (e.g., ~40% of workers with 20+ years of latency had some abnormal findings from the chest radiograph, pulmonary function test, or physical examination). Risks to spouses, on the other hand, were much lower than expected. Publicity and union assistance had allowed us to identify and contact over 1,300 former workers. During the course of the screening program, the department had received from the company 3,900 abstracted personnel records for workers employed during the period when asbestos was used (1958-1974). These records contained many duplicates but also omitted many known workers. Based on these findings, the legislature appropriated \$250,000 over 2 years to enable the department to identify, trace, and notify the estimated 2,000-3,000 workers who had not been previously notified or screened. A follow-up evaluation of the initial notification/screening program was also planned. The department did not recommend additional screening at that time, although an ongoing screening program was attached to a legislative bill that was subsequently vetoed.

Follow-Up Evaluation Survey

During the initial notification/screening, over 1,300 workers and their spouses were notified and invited to screening. (Most who declined to participate had been part of the Union screening and did not want to "take-up" a screening slot from an unscreened worker or spouse.) A follow-up survey of these 1,300 workers (whether screened or not) was conducted ~1 year following the screening. The survey was designed to examine a variety of attitudes, behavioral outcomes, sources of information, resources, and knowledge. Of a priori interest were differences between those who were screened and those who were not screened by the state. Also of interest was how these outcomes varied depending on the individual's screening results. The survey was pilot tested with a sample of former workers. A mailed survey was used, with two mail follow-ups. Those who failed to respond were contacted by a telephone interviewer. The overall response rate was 92%. Among the findings, the survey

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confirmed that over 95% of the respondents were supportive of their having been notified of their health risks and believed that other former workers should be notified. About one-third had discussed their exposure or screening results with a doctor. A full report on the survey results is in preparation.

Identification and Tracing of Remaining Workers

The 3,900 personnel record abstracts received from the company were put into a database. After elimination of duplicates, ~3,300 records remained. Records were then compared with those already known through the initial notification/screening program. Approximately 2,200 previously unknown workers were identified. These workers were traced through a combination of mechanisms, including motor vehicle records, a national credit information service, and the state department of revenue. Approximately 1,800 workers could be traced using these means. Former workers were located in 46 states.

Notification of Former Workers

A notification packet was sent to the 1,800 newly traced workers in June, 1991. This notification differed from the original in that no free medical screening was offered, and it was based on the results of the screening and the follow-up survey. This packet consisted of a personalized cover letter, a question-and-answer fact sheet, a National Cancer Institute brochure about asbestos exposure, and a confidentiality statement required by the court order through which the personnel records were obtained. Readability of the material was assessed with the aid of a computer program and by pilot testing through an adult education class.

Additional Cohort Identification and Tracing

Because it had been ascertained that the personnel records provided by the company were incomplete, an additional step was taken to identify former workers. The company was asked and subsequently agreed to request IRS 941 records from the Social Security Administration. These are records that were filed by the company each quarter listing the names, social security numbers, and wages for each employee. Such records have been used in epidemiologic studies to identify or to confirm the completeness of occupational cohorts [Marsh and Enterline, 1979; Marsh, 1982; Enterline and Marsh, 1982]. In July, 1991, we received ~2,000 pages of names and social security numbers (~44 names per page), representing 68 successive quarterly rosters between 1958 and 1974. Legibility was highly variable. These records are currently being keyed and compared to the roster of about 3,100 known workers. Previously unknown workers will then be traced and notified. This phase was budgeted at \$25,000 for data entry, tracing costs, and other expenses. This cost does not include the epidemiology support (25% time over 6 months).

Legal Notification

One potential legal implication of a screening program is its possible impact on applicable statutes of limitations for workers' compensation or product liability suits. Providing an individual with evidence of asbestos-related disease in a screening program may, in effect, start tolling the statute of limitations. Because of this possibility, the state office of the attorney general sent a personalized letter to screened individuals alerting them of the statute of limitations issue and suggesting that they

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consider seeking legal advice. Because of a provision in the court order (under which the company provided personnel and social security records), it was not clear at the end of 1991 whether this legal notification will be sent to workers identified through these record sources.

Future Activities

Several future activities are possible. For example, important new research on screening modalities or on chemoprevention for lung cancer might be the basis of an additional notification to this high risk cohort. A substantial investment of state resources has been dedicated to the establishment of an occupational cohort with significant, and previously unknown, asbestos exposure. Another productive use of this information would be to examine the cancer morbidity of this cohort through record linkage with the statewide cancer surveillance system. A classic cohort mortality follow-up would also be warranted, although it would be much more costly.

CONCLUSIONS

A worker notification program may entail many different activities. Depending on the scope of these activities, such programs can be very complex and costly, much more so than a typical occupational follow-up study. The cost of the notification and screening program for asbestos-exposed Conwed workers will likely exceed \$650,000 by its completion. During the course of this program, ~4,500 workers will have been identified and the majority traced. Approximately 1,100 workers will have been screened and another 3,400 workers will have been notified but not screened. In addition, 451 spouses will have been screened. Over 11,000 personalized letters will have been sent to individuals or their physicians.

Much of the cost and complexity of the Conwed program was due to two factors: initially it was not known how many workers were employed at the plant and who they were, and it was not known to what extent workers and their family members may have been exposed to asbestos. These and other information gaps resulted in the extensive cohort identification and tracing as well as the medical screening. The inclusion of the medical screening, in particular, increased the complexity by an order of magnitude. The decision to institute medical screening should be made with careful consideration of the diverse implications of screening to the individuals, communities, and agencies involved.

An additional, although not major, cost of this program was the follow-up survey of those 1,300 workers who were initially notified and invited (along with their spouses) to the screening. Few evaluations have been reported in the literature, especially for asbestos cohorts [Freimuth and Van Nevel, 1981; Tillett et al., 1986; Houts and McDougall, 1988; Meyerowitz et al., 1989; Lowinger, 1990]. Due to time and cost considerations, this evaluation did not include a true control group (i.e., a group of comparable age and sex who had not been informed about and/or screened for asbestos exposure). Consequently, important factors such as measures of stress and anxiety could not be examined. Within the data set, however, we could examine differences in opinions, behaviors, and knowledge based on whether the persons were screened; on whether they had been informed of abnormal test results; on whether they had insurance coverage; and on socioeconomic, demographic, and other factors. In developing the protocol and resources for notification, an evaluation component

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should be carefully considered, especially insofar as methodological and philosophic issues of notification are still being resolved.

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